Burden among Caregivers of Patients with Mental Illness

Akanksha Goswami[1], Rajani Rana[2], Goldi Ramola[3],

Shikha Joshi[4], Nisha Joshi[5], Neha Juyal[6], Pooja Godiyal[7]

[1,2,3,4,5,6]PG Student, State College of Nursing, Dehradun, Uttarakhand, India

[7]Assistant Professor, State College of Nursing, Dehradun, Uttarakhand, India

ABSTRACT

Background: The well-being of family caregivers of mentally ill patients has often been ignored despite of the fact that caregivers have a significant role in supporting the patient both psychologically as well as physiologically. This study examined the level of burden experienced by family caregivers while caring for their mentally ill patients. **Objectives:** To assess the burden among caregivers of patients with mental illness. **Materials and Methods:** A quantitative approach with a descriptive design was used in the study. The study was conducted in O.P.D of Doon Hospital, Dehradun. Probability Consecutive sampling technique was used to collect data from 550 subjects. The duration of the data collection was 4 months. Burden assessment scale was used to assess the burden among caregivers of patients with mental illness. **Results:** The mean score was 54.22 with a standard deviation of 7.851. The majority of caregivers 65.09% had a higher level of burden. On the other hand, 34.90% of caregivers had a lower level of burden. **Conclusion:** It is concluded that more than half of the caregivers experienced higher level of burden which makes it apparent that most caregivers of mentally ill patients feel burdened in caring for their patients. Supportive measures, raising awareness and reducing the stigma surrounding the mental health can be helpful in addressing as well as reducing the burden of caregivers.

KEYWORDS: Burden, Caregivers, Mental illness, Patient

Introduction

Mental Health is a state of mental well-being that enables people to cope with the stresses of life, realise their abilities to learn well and work well and contribute to their community (WHO)[1]. Mental health is more than the absence of mental disorders. It exists on a complex continuum which is experienced differently from one person to the next with varying degrees of difficulty, potentially different social and clinical outcomes[2]. Hence, it is necessary to support people with mental illness for the betterment of society. In 2019, 1 in every 8 people, or 970 million people around the world were living with a mental disorder, with anxiety and depressive disorders the

most common while in 2020, the number of people living with anxiety and depressive disorders rose significantly because of the COVID-19 pandemic[3]. Mental illness brings with it a range of consequences not only for the individual concerned but also for the primary caregivers which can be family members, friends or relatives. Family plays a vital role in the care of a mentally ill patient and can also suffer from mild to severe burden. Caregiver burden is defined as the stress that derives from caring for others while caregiver burden is the sensation of emotional or physical tension felt by caregivers[4]. In India, about 20% caregivers face a lot of strain, ill health, and disrupted family life, with literature suggesting an increasing concern about their ability to cope. The needs of caregivers, especially of mentally ill patients are given low priority in the current health-care setting in India. Family caregivers are important aspects for healthcare providers in facilitating the recovery process among people with mental illness[5]. Caregiver's own psychological and intrinsic factors, including self-esteem and psychological distress, are also strong factors associated with quality of life. Common psychological distress among caregivers includes anxiety and depression[6]. It is necessary to assess the burden among caregivers so that a solution can be found.

Materials and method
Study Design
This study was conducted in the O.P.D of Doon Hospital, Dehradun, India, from 1 August 2023 to 30 November 2023. The burden of caregivers of mentally ill patients was assessed using the Burden Assessment Scale. A total of 550 subjects who fulfilled the inclusion and exclusion criteria were included in the study.

Inclusion Criteria
Caregivers who were present at the time of data collection and were available in psychiatric O.P.D. with their patients.

Exclusion Criteria
Caregivers who were not willing to participate.

Tool
Socio demographic variable
Demographic data consists of two sections –
Caregiver's data: It includes age of caregiver, years living with the patient, gender, educational status, marital status, domicile, type of family, household income, money spent on treatment, family history of mental illness, employed, kinship with patient.

Patient's data: It includes age of patient, gender, diagnosis, average age of onset, number of hospitalization in OPD/IPD in last three months, total

number of hospitalization, employment, pharmacological treatment, any medical benefit allowances

Burden Assessment Scale (BAS)
The Burden Assessment Scale (BAS) was developed by Rein-Hard and Horwitz. This scale is a 19-item, self-administered scale to assess the burden on families with a seriously mentally ill family member. Items 1-10 assess objective consequences, including financial problems, limitations on personal activity, and household disruptions. Items 11-19 measure subjective consequences, including shame, stigma, guilt, and resentment. Each item is rated on a 4-point scale (1 = not at all; 4 = a lot). To score the BAS, ratings from each item are added together to give a total score, with higher scores indicating greater levels of caregiver burden.

Statistical analysis
The data of level of burden among caregivers of mentally ill patients was presented as mean ± standard deviation. Frequency and percentage distribution of caregivers and mentally ill patients was analysed.

RESULTS
In this study, 550 caregivers of mentally ill patients with age ranging between 18-80 years and mentally ill patients with age range between 7-60 years were included. The mean age of caregivers was 39.22 ± 15.55 while mean age of mentally ill patients was 29.40 ± 14.84. The mean score of level of burden among caregivers was 54.22 with standard deviation of 7.851. This shows that there was severe level of burden among most of the caregivers while caring for the mentally ill patients.

Table: 1 depicts that majority of caregivers belonged to the age group of 15-35 years 176 (32%). Majority of caregivers were living with the patient from 1-10 years 386 (70.18). In gender, majorly caregivers belonged to the male category 319 (58%). In educational status, most of the caregivers had secondary education 393 (71.45%). Majorly caregivers were married 418 (76%). In domicile, majorly caregivers belonged to Uttarakhand 500 (90.90%). In type of family, caregivers majorly belonged to nuclear family 373 (67.81%). Majority of caregivers were having household income of 15001-30000 that is 315 (57.27%). Major money spent on the treatment was from 1000-2500 that is 402 (73.09%). Majorly were not having any family history of mental illness 298 (54.18%). Majority of caregivers were employed 305 (55.45). In kinship with patient, majority of caregivers were spouse 132 (24%).

Table: 2 depicts that majority of mentally ill patients belonged to age group of 1-20 years 320 (58.18%). In gender category, majority mentally ill patients belonged to the male category 280 (50.90%). Majority of patients were having diagnosis of depression that is 110 (20%). Majority of patients had 21-40 years of age at onset of the mental illness 325 (59.09%). In number of hospitalization in last three months, majorly fall in the interval of 3-5 that is 270 (49.09%). In total no. of hospitalization, majorly fall in the interval of 0-2 that is 325 (59.09). Majority of patients were not employed 440 (80%). Majority of patients were having some sort of pharmacological treatment 490 (89.09). Majority of patients had some kind of medical benefit allowances 390 (70.90).

Figure: 3 shows that majority of the caregivers that is 358 (65%) were facing higher level of burden while only 192 (35%) were facing lower level of burden while caring for their mentally ill patients.

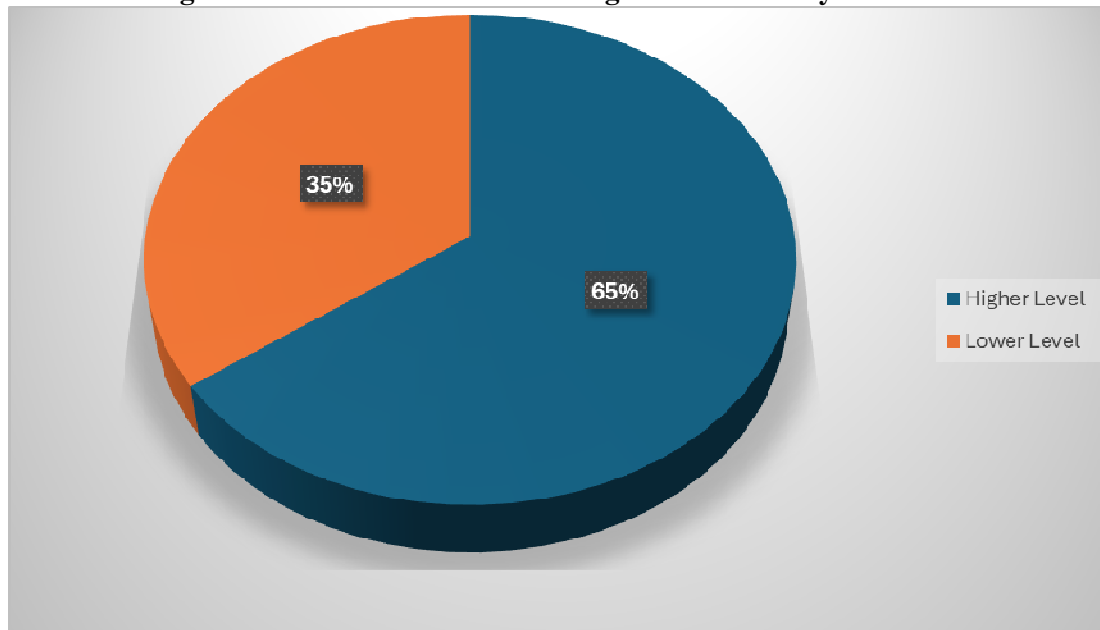**Table:1 Selected demographic variables of caregivers of mentally ill patients**

N=550

S. No.	Variables	Frequency	Percentage (%)
	Age of caregivers		
	18-38 years	315	57.27
1.	39-59 years	176	32
	60-80 years Mean of age- 39.22	59	10.72
	Years of living with the patient		
2.	1-10	386	70.18
	11-20	122	22.18
	21-30	42	7.63
	Gender		
3.	Female	231	42
	Male	319	58
	Educational status		
	No formal education	23	4.18
	Primary education	47	8.54
4.	Secondary education	393	71.45
	Graduate	52	9.45
	Post graduate	35	6.36
	Marital status		
5.	Married	418	76
	Unmarried	127	23.09
	Widow	5	0.90
6.	**Domicile**		
	Uttarakhand	500	90.90
	Uttar Pradesh	38	6.90
	Himachal Pradesh	10	1.81
	Bihar	2	0.36
	Type of family		
7.	Nuclear	373	67.81
	Joint	152	27.63
	Extended	25	4.54
	Household income		
8.	1000-15000	151	27.45
	15001-30000	315	57.27
	Above 30000	84	15.27
	Money spent on treatment		
9.	1000-2500	402	73.09
	2501-5000	96	17.45
	Above 5000	52	9.45

10.	**Family history of mental illness**		
	Yes	252	55.45
	No	298	54.18
11.	**Employed**		
	Yes	305	55.45
	No	245	44.54
12.	**Kinship with patient**		
	Father	126	22.90
	Mother	95	17.27
	Spouse	132	24
	Brother	52	9.45
	Sister	47	8.54
	Child	79	14.36
	Other	37	6.72

Table:2 Selected demographic variables and personal history of mentally ill patients

N=550

S. No.	Variables	Frequency	Percentage (%)
1.	**Age**		
	< 20	130	23.63
	21-40	320	58.18
	41-60	100	18.18
2.	**Gender**		
	Male	280	50.90
	Female	270	49.09
3.	**Diagnosis**		
	Schizophrenia	23	4.18
	ADHD	56	10.18
	Depression	110	20
	Dementia	45	8.18
	Anxiety disorder	85	15.45
	OCD	42	7.63
	Aggression disorder	32	5.81
	Alcohol abuse	80	14.54
	Mood Disorder	10	1.81
	Learning disorder	28	5.09
	Autism	10	1.81
	Eating disorder	20	3.63
	Mental retardation	9	1.63
4.	**Average age at onset**		
	1-20	131	23.81
	21-40	325	59.09
	41-60	94	17.09
5.	**Number of hospitalization in OPD/ IPD in last three month**		
	0-2	200	36.36
	3-5	270	49.09
	6-8	80	14.54
6.	**Total number of hospitalizations**		
	0-2	325	59.09
	3-5	180	32.72
	6-8	45	8.18
7.	**Employed**		
	Yes	110	20
	No	440	80

8.	Pharmacological treatment		
	Yes	490	89.09
	No	60	10.90
9.	Any medical benefit allowances		
	Yes	390	70.90
	No	160	29.09

Figure:3 Level Of Burden On Caregiver Of Mentally Ill Patient

DISCUSSION

Caregivers play a crucial role in supporting and caring for their mentally ill patients. Their struggle of caring for mentally ill patients and facing stigma regarding mental illness is always marginalized, undervalued, and invisible to medical services[7].

In this study total of 550 caregivers of mentally ill patients were taken from age range between 18-80 years and their mean score of level of burden was 54.22. Majority of the caregivers that is 358 (65%) were facing higher level of burden while only 192 (35%) were facing lower level of burden while caring for their mentally ill patients. Similarly, a study conducted by Walke C.S., Chandrasekaran V.,[1] and Mayya S.S.(2018) on caregiver burden among caregivers of mentally ill individuals and their coping mechanisms consists of 320 caregivers who were taken through convenient sampling technique in two private tertiary care centers and one public secondary care center located in Udupi taluk, Karnataka. The results of this showed that severe burden accounted for 40.9% and moderate for 59.1%[8].

Dhami J., Tuladhar S. (2021) conducted a study on Burden of Care among Caregivers of Mentally Ill Patients in Kathmandu, Nepal. A total of 97 family members was selected consecutively from the psychiatric outpatient department (OPD) and wards of Mental hospital. Structured interview-based questionnaire was used. The study results revealed that 40.2 % of the caregivers had mild burden, 27.8% had moderate burden, 25.8% experienced little or no burden and 6.2% experienced severe burden[9].

The mean age of caregivers was 39.22 ± 15.55 while mean age of mentally ill patients was 29.40 ± 14.84. In a similar study, conducted by Gandhi S. and Thennarasu K. on Burden among Caregivers of Clients with Depression in Banglore, India. A total of 30 caregivers of in-patients with depression recruited using convenience sampling technique in a specific tertiary care neuro-psychiatric hospital at Bangalore. This study revealed that 43.3% of the caregivers were males, 56.7% were females; 80% were married and 20% were single and 50% of the patients were diagnosed as BPAD with severe depression. The mean age of the patients was 36.7 ± 16.3. Caregivers age ranged from 16-67 years with Mean age of 42.9 ± 15.5 reflecting that caregivers were in their most productive ages[10].

The present study as well as the above studies concludes that caregivers of the mentally ill individuals do undergo a lot of burden. Hence, there is a need to develop strategies that can help them to address and reduce their burden by providing them with a support structure as well as counseling services

LIMITATIONS

There were many repeated patients in the O.P.D. who were coming for the follow ups.

CONCLUSION

On the basis of this study findings, it is concluded that the maximum number of caregivers had higher level of burden while caring for the mentally ill patients. The findings of this study would be useful for authorities of mental hospitals in recognising the baseline information of caregivers and severity of burden faced by them.

REFERENCES

[1] Mental Health - PAHO/WHO | Pan American Health Organization [Internet]. [cited 2023 Dec 22]. Available from: https://www.paho.org/en/topics/mental-health

[2] Mental health [Internet]. [cited 2023 Dec 22]. Available from: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response

[3] Mental disorders [Internet]. [cited 2023 Dec 22]. Available from: https://www.who.int/news-room/fact-sheets/detail/mental-disorders

[4] Dhami J, Tuladhar S. Burden of Care among Caregivers of Mentally Ill Patients. J Pharm Pract Community Med. 2021;7(3):44-5

[5] Walke SC, Chandrasekaran V, Mayya SS. Caregiver Burden among Caregivers of Mentally Ill Individuals and Their Coping Mechanisms. J Neurosci Rural Pract. 2018;9(2):180–5.

[6] Cheng WL, Chang CC, Griffiths MD, Yen CF, Liu JH, Su JA, et al. Quality of life and care burden among family caregivers of people with severe mental illness: mediating effects of self-esteem and psychological distress. BMC Psychiatry. 2022 Oct 31;22:672.

[7] Ebrahim OS, Al-Attar GST, Gabra RH, Osman DMM. Stigma and burden of mental illness and their correlates among family caregivers of mentally ill patients. J Egypt Public Health Assoc. 2020 Nov 9;95(1):31. doi: 10.1186/s42506-020-00059-6. PMID: 33164132; PMCID: PMC7649189.

[8] Walke SC, Chandrasekaran V, Mayya SS. Caregiver Burden among Caregivers of Mentally Ill Individuals and Their Coping Mechanisms. J Neurosci Rural Pract. 2018 Apr-Jun;9(2):180-185. doi: 10.4103/jnrp.jnrp_312_17. PMID: 29725166; PMCID: PMC5912021.

[9] Dhami J, Tuladhar S. Burden of Care among Caregivers of Mentally Ill Patients. J Pharm Pract Community Med. 2021;7(3):44-5.

[10] Gandhi S., Thennarasu K. Burden among Caregivers of Clients with Depression – A Scientific Study. International Journal of Advanced Nursing Science and Practice 2012, Volume 1, Issue 1, pp. 20-28.